



From the Chair



A spider has set up home by our mailbox and as I carefully extract the mail trying hard not to damage the web it sets me musing on what makes a network strong. The spider needs strong anchor points to attach its web. Our spider has used the brick gatepost and the hedge. The web has a defined structure which adds to its strength. It is also flexible

and can be adapted to meet changing circumstances such as the hedge being cut.

Our networks need strong anchor points too. In our case these are the health services provided to children and young people through DHBs. Just like our spider some of the anchor points are stronger than others. Stronger services can share knowledge expertise and skills with those needing help to develop. Our Clinical Networks can provide this.

The web or network needs to be strong to do its job. Like spiders' webs our networks have a defined basic structure which gives them strength.

In this issue of CYNet we have profiled important infrastructure elements which contribute to the strength of all clinical networks for children and young people.

Liz Segedin discusses how the Paediatric Society of New Zealand's Transport Special Interest Group is working to make transfer of children and young people between health care providers safer. We all know that transporting an acutely unwell child from one place to another is inherently risky. We also all know that unwell children are transported in many different ways.

The PEWS chart described by Wendy Sullivan is another important component of the infrastructure to ensure that safe quality health care is provided to children and young people both during transport and on the wards. Developing a single chart that meets the hour by hour needs of children in Intensive Care as well as those with conditions that require recognition of changes over days has been a challenge which the team has risen to.

The MOM – Map of Medicine – is coming to a DHB near you. David Newman, President of PSNZ and until recently, Clinical Director of Paediatrics at Waikato DHB emphasises the importance of clinician input to ensure that the clinical pathways are relevant to our needs and population. Consistency across the country is really important and the MOM is preferred by the National Health Information Technology Board.

There are other important clinical tools which need to be part of the national paediatric services and child health infrastructure and we hope to profile these in more detail in the future. The Advisory Group and secretariat have facilitated discussion between interested parties to ensure that we get an appropriate, nationally-consistent growth chart and work on this is ongoing. A National Paediatric Medication Chart is being developed and this will contribute to the important issue of medication safety. The Paediatric Society of New Zealand was able to support the launch of the New Zealand Formulary for Children in November 2013 at the Annual Scientific Meeting in Dunedin. The link is <http://nzfchildren.org.nz/> and the NZFC can also be reached from the New Zealand Formulary home page: <http://nzformulary.org/> - do bookmark it or add it to your favourites.

Also in this issue Scott Macfarlane has provided an update on the National Child Cancer Network. He underlines the importance of working with NGO partners and other organisations. This is crucial to all of our clinical networks.

Items on the Paediatric Surgeons Special Interest Group, awareness of sleep disorders in children and a proactive approach to vulnerable infants from Waitemata DHB are also included. So if you are involved in an activity to improve healthcare for children and young people do email Lauren so everyone can learn from your experience.

Lastly... I have a dream... My dream is to see integration of DHB IT systems so that when an acutely unwell child presents to a DHB while on holiday, those clinicians caring for the child can access relevant information from the child's clinical record. Yes, there must be appropriate security and respect for the confidentiality of clinical information, but this should not place a road block in the path of timely clinical care of the highest quality. We have a huge advantage in New Zealand – it is the NHI – we can do it.

Rosemary Marks

National Child and Youth Clinical Network Advisory Group

National Child Cancer Network – two years on

An Interview with Scott Macfarlane, Clinical Leader

From the outset, the National Child Cancer Network (NCCN) has focused on delivering outcomes that have a real impact on the quality of care and support for children with cancer and their families.

“Everything we do has to work towards making sure that kids receive the same quality of care regardless of who they are or where they live in this country” says Scott Macfarlane, Clinical Leader of the Network. “The reality check has been having our NGO partners as part of our team, constantly challenging priorities and reminding us that kids and their families are at the centre of this network.”

Two years in, the rewards for the NCCN team are clear. “I feel like we’ve achieved a lot” says Scott. “The key has been using the experience, ideas, and innovations of all the experts we have in our medical, nursing, allied health and NGO ranks and turning them into simple, action plans with committed champions”.

“We’re relying on the time and inputs of some seriously busy health professionals” he adds. “We use paid NCCN person-power wherever possible, to do the time consuming research, drafting and consultation involved in implementing these strategies. That lets our roped in working group members get back to dealing with actual kids and their families.”

The overall work programme for the Network has involved putting robust infrastructure in place to give a spine to a national programme of evidence-based best practice at the same time as implementing solutions to fix specific gaps that have been identified in service delivery.

Scott highlights a nationally agreed approach to negotiating Service Agreements between Specialist and Shared Care Centres as a key achievement that has introduced a whole new level of consistency and transparency to service delivery.

A standardised template requires Shared Care and Tertiary Centres to examine how they work together to provide seamless care for children with cancer. This involves confirming and documenting guidelines, services and standards of care are in place; describing local approaches to service delivery; and identifying service and professional development needs and goals.

The process creates a unique opportunity for extended

Multidisciplinary teams to come together and focus exclusively on child cancer services and develop a shared understanding of who does what, where and when. It has provided a catalyst for developing simple, workable solutions to address everyday communication and information sharing gaps both within and across services.

“It’s amazing what happens when you put teams together in the same room and give them uninterrupted time to look at an issue. Things that have been a pain in the neck to deal with on a day to day basis get broken down and fixed in minutes” says Scott Macfarlane.

To date NCCN has made their way around at least half of the Shared Care Centres. Physically visiting facilities and meeting with MDTs has allowed the Network to develop a national picture of child cancer services in this country. It is no surprise to Scott that “we’ve uncovered many common frustrations and some really innovative local solutions that we have been able to share with other centres. We’ve also been able to put some really simple fixes in at a national level to deal with recurring concerns across DHBs.”

Another important cornerstone of the Network’s programme is their electronic library of more than 180 National Supportive Care Guidelines that are available on the Starship website. By locating these guidelines alongside those of other specialty groups they have broken down barriers that previously existed for Shared Care Centres to access consistent guidance for managing the complications of childhood cancer and chemotherapy.

In the past eighteen months focused working groups have drafted key guidelines to address new technologies, inconsistencies in service delivery across DHBs and other gaps identified as significant barriers to quality of care for children with cancer.

Most significant, are guidelines on Fertility Preservation for People with Cancer, Immunisation of Children During and After Cancer Therapy, Dental Complications of Treatment for Childhood Cancer and Surveillance and Imaging.

“It has been fantastic to receive reports that our national guidelines are routinely referenced in Shared Care Centres across the country and to see steady increases in website traffic from both New Zealand and International Centres, says Scott. “For some reason we’re

really popular in Cairo!”

The Network now have more than 170 nurses, allied health professionals, NGO workers and doctors signed up as members of their members’ portal. This online workspace is increasingly a platform for sharing information and ideas, generating discussion and debate, archiving key documents and facilitating planning across our broad child cancer service provider community.

Over the past 18 months, NCCN has been heavily involved in a Ministry of Health review of Services for Adolescents and Young Adults with Cancer. “While this isn’t our core business,” says Scott “there is a clear overlap with Child Cancer Services. This is a vulnerable group of young patients who fall across and sadly, sometimes between, child and adult services – not just in cancer treatment, but across the health system.”

The Network will continue to be involved in the planning and implementation of service delivery improvements in this area, alongside their adult colleagues. “It feels like it’s the right time to move on service gaps in this area” says Scott. “We now have robust data. While we still need to delve deeper, we’ve got some clear flags about where we need to focus our efforts and insist on change. We’ve got CanTeen and a group of clinicians from across Cancer Services ready to drive things forward.”

Looking ahead

The secretariat of the National Child and Youth Clinical Network Advisory Group have been in discussion with our colleagues in the Ministry of Health on how Clinical Networks can be supported after the current PSNZ contract with MOH ends in June.

We have also had a number of key people resign from the advisory group; the secretariat is currently working on how best to replace their excellent skills.

In particular we would like to acknowledge the vision and hard work of Advisory Group foundation members, Dr Nick Baker and Professor Barry Taylor.

“Overall” says Scott, “the Network is in great health. Our current contract with the Ministry runs through to the end of June 2015 and we are expecting to complete some further significant pieces of work before then. One of our next priorities - linked to the AYA work - is resolving how we better transition the care of our longer term and older follow-up patients. It’s great to know that we’re in a strong position to take on any additional new initiatives that emerge over the next twelve months.” ●

Inter-hospital transfers

Moving sick and injured children between hospitals will become safer when the work of The Paediatric Transport Committee is finalised over the coming months. They have been working on a revised set of guidelines, the first of which were published in 1995. The guidelines are in the final phase of consultation and have had the input of the Paediatric Society Council, neonatologists, transport nurses, intensivists and paediatric specialists and nurses. The PEWS score (see story last page) will be part of guidelines.

The guidelines will include some minimum requirements for the documentation of vital signs and expectations for handover documentation based on age appropriate PEWS charts. Spokesperson for the committee, Elizabeth Segedin says that while we don’t know exactly how many children are moved between hospitals each year, it would number in thousands. “The most difficult transfers are those children who are not in ICU but still need a lot of support,” she says. “These children are often not catered for by existing ICU transport systems so we need a standardised system around them when they are being transferred. Each



DHB has a different system and record differently so we need to assist by providing robust tools for measuring clinical condition in transfer and preparing for a good handover,” she said. Each region is being encouraged to look at its own transport systems.

Once ratified, the Transport Guidelines will be on the Paediatrics Society website and the Starship website.

Elizabeth Segedin

Surgical Special Interest Group

Bridging the gap between paediatricians and paediatric surgeons is the aim of the Surgical Special Interest Group (SIG). Neil Price, who is chair of this newly revitalised group says that because only four DHBs in the country have dedicated paediatric surgeons, equity of access to appropriate care for all children regardless of where they live continues to be a challenge. "Paediatricians and paediatric surgeons care for the same patient group however we have different training, different professional groups and separate CME meetings. We want to improve access of paediatric trainees to a surgical education to give a better understanding of surgical issues in children," he says.

In addition, Neil wants to see access channels to paediatric surgeons for advice on referrals and updates improved, as well as improving complimentary service development. A good example of this is the planned Percy Pease Symposium in September. Well known to most of you, the late Mr Percy Pease was New Zealand's first full time Paediatric Surgeon. He had previously worked and trained as a Paediatrician in his native South Africa, subsequently retraining in England before coming to New Zealand. Percy's career was laudable in many respects but there are a few themes that ran through it that we wish to expand upon with our SIG work.

Firstly, he had a close working relationship with his medical colleagues, gaining him the recognition of being labelled 'the Paediatrician's Paediatric Surgeon'. The second is his interest in fostering interdisciplinary initiatives that improved healthcare of children, especially his involvement in the evolution of a multi-disciplinary children's cancer service and Paediatric Intensive care. Thirdly, we wish to recognise some of his special interest areas such as thoracics and urology. Finally Percy had

a strong interest in out-reach services both around New Zealand and the Pacific, in the interests of providing appropriate care to all children regardless of where they reside.

The aim of the symposium has been to, firstly, provide an informative update for paediatricians, general practitioners, nurses and allied medical staff from around New Zealand to contribute to their care of New Zealand's children within and outside of the Greater Auckland area. We hope to foster the ongoing sense of collegiality between all professionals involved in the care of children, both medical and non-medical.

It has been run twice so far but I hope we can continue to offer this symposium as an annual event for ongoing medical education, updates and as a forum to discuss issues confronting our combined attempts to deliver meaningful and relevant healthcare to children who need it.

This year it will be 5th September (first Friday in September) and we plan to use the day to explore paediatric healthcare delivery in the greater South Pacific Region, another of Percy's passions. We will look at some of the fascinating work that is already occurring, hear about the ongoing unmet need, and discuss what can be done going forward to provide a sustainable, non-fragmented appropriate service. We hope that many of you can make it.

One of the great challenges facing paediatric surgical services in NZ is that paediatric surgeons are only employed by four of the DHBs. Equity of access to appropriate surgical care for all children and young people regardless of their DHB of residence in an appropriate and sustainable way looks to be one of the big challenges facing our group in the near future. ●

WDHB vulnerable infant forum

Waitemata DHB has been operating their Te Aka Ora Vulnerable families' forum since July 2012. The forum was established with the aim of identifying families vulnerable to issues adverse to new babies during pregnancy. This window of opportunity to work with the families to prepare for the arrival of the new baby and after the mother's discharge is proving of significant benefit. The forum consists of experts in Midwifery, Women's Social Work, Maternal Mental Health, Addictions in Pregnancy, Child Youth and Family Service, and specific cultural expertise. Agencies that work in the area of parent and family support such as Well Child providers and family start are co-opted onto the forum as needed for ongoing family support

The forum identifies a key worker and makes recommendations to those working closely with the family. The forum is also responsible for ensuring the documented care plans are available for other health workers who are in contact with the family, such as the family doctor.

Families can be referred to the forum by any person working with the family so although it is generally the LMC it can also be a public health nurse, or CYF social worker etc. The care plans are sent to the LMC but are held electronically on the Concerto system. Discharge plans are shared with GPs and Well Child providers and are also stored electronically on the Concerto system. ●

Sleep issues in children

Dr Liz Edwards is passionate about raising the issues of sleep disorders in children. She estimates that approximately 25% of all children experience some type of sleep problem during childhood. While many are transient, such as bedtime resistance and night terrors, more serious disorders can have a huge impact on both the child and their family. Obstructive Sleep Apnoea (OSA) can account for around 2 – 3% of sleep disorders in children. (OSA accounts for around 7% of sleep disorders in adults).

OSA in children can be much more difficult to diagnose in children as they may not snore like adults, but have noisy or 'heavy' breathing. In adults the impact of OSA can be gauged by numbers of workplace and road traffic accidents. However in children, Liz counts lost school days, hospitalisations, quality of life, neurocognitive sequelae and second generation health issues such as hypertension, diabetes and metabolic syndrome as possibly resulting from OSA in children. Hyperactivity may also manifest due to poor sleep quality.

In New Zealand Liz thinks awareness of sleep disorders in children needs to be raised at a primary care level. The BEARS mnemonic, below, is a useful tool to elucidate a sleep history as a general screening tool.

An adaptation of the "BEARS" mnemonic:

B Bedtime issues (trouble going to bed or trouble falling asleep)

Question "Does your child have any difficulty going to bed or falling asleep?"

E Excessive daytime sleepiness/excessive disruptive symptoms in children

Question "Is your child difficult to wake in the morning, act sleepy, or are they overactive, inattentive or easily frustrated?"

A Awakenings at night

Question "Does your child wake up regularly at night?"

R Regularity and duration of sleep (bedtime, wake time, average sleep duration)

Question "What time does your child go to bed and get up on schooldays? weekends?"

S Snoring/Sleep Disordered Breathing (SDB)

Question "Does your child have noisy breathing or snore on most nights?"

Reference - Chamness JA. Taking a pediatric sleep history. Pediatric Annals July 2008 37(7) 502-508).

In most cases, an adenotonsillectomy is a highly effective treatment, offering a solution in 70 -80% of cases. Children most at risk of OSA include the obese and those with underlying medical issues eg Downs syndrome or neuromuscular weakness eg Duchennes muscular dystrophy. Liz firmly believes that just because the issue is under-resourced in New Zealand, it does not mean that we should not be looking for it. "OSA can cause huge issues for children and their families. We tend to under-recognise and under-appreciate the impact that OSA can have on people's lives," she says. "I just want doctors to think more about sleep, check the size of tonsils and adenoids and take a sleep history."

Liz says, when available an overnight oximetry can be helpful to assess operative risk in some children with OSA but it cannot be used to rule out OSA so has to be interpreted with care. A formal overnight sleep study (polysomnogram) may still be indicated. "It is documented that the sooner OSA is diagnosed in children, the better the outcome can be for them," says Liz. ●



Map of medicine

Using the decision and pathway tools such as the Map of Medicine has potential benefits for all clinicians in New Zealand, according to Dr David Newman, the new President of the NZ Paediatric Society. The Map of Medicine is an English based decision support tool that provides on line care pathways based on international best practise evidence. Individual maps can be for topics from constipation to depression and can be localised to account for regional needs and conditions. The Waikato DHB, including primary care practices, have been using this interface for six months and are experiencing the benefits of a streamlined decision tree which is based on best international evidence. The pathways can be modified to accommodate say different medications, generic drugs or conditions prevalent in different settings.

However, according to David, clinicians need to engage now to ensure that our best New Zealand practice is incorporated into the tool. "Because it is possible that the Map may become the clinical pathway of choice, the more our own clinicians have input into it, the more useful it will be," he said. "The Map development process is being driven by the needs of primary care for meaningful decision support but also includes secondary care management sections so has wide applicability. We need to influence the pathways to match our local needs while ensuring fidelity to best evidence practice. The local buy-in between primary care and secondary care clinicians has been fantastic," he said. "Between us, we have created 35 pathways especially for New Zealand clinicians, five of which are specifically paediatric, and more are in development."

The Map of Medicine, which originated in the UK is a recognised authority as a reference source of evidence-based,

condition-specific pathways that are constantly updated. They are accredited by many Royal Colleges and societies and have international clinical content, with contributions from 7,200 journals articles as sources of guidance for 300 accredited international pathways.

This empowers clinicians to deliver better care locally by adapting care pathways to improve patient journeys, growing the 1,400 localised pathways to accommodate local conditions. This can help ensure that patient journeys are more streamlined, consistent and appropriate to local resources. This in turn can contribute to saving precious health resources while delivering better patient care.

The Map of Medicine is user-friendly and can be used during a consultation by focussing on the elements relevant to the clinical situation. More detailed information is available as required as a part of each Map. As with any good decision support tool this may be especially useful in more remote settings where clinicians may be working alone.



Dr David Newman

David Newman is a Developmental and General Paediatrician who has worked from the Child Development Centre at Waikato Hospital for the past 16 years. He is also the Clinical Director of General Paediatrics for the past 8 years and President of the Paediatric Society of New Zealand since December 2013. Reflecting

his interest in paediatric administrative and clinical regional networks David and Dr Steve Bradley founded the Midland Paediatric Clinical Directors' Group in 2010. This group has enhanced collaboration and facilitates the development of consistent approaches to clinical issues, such as air blending for neonatal resuscitation, across the Midland Region.

PEWS

A new tool for healthcare workers is set to help early identification of children who are at risk of deteriorating very quickly in a ward situation. The PEWS (paediatric early warning score) chart has 7 parameters – heart rate, respiratory rate, respiratory distress, oxygen requirement, O₂ levels in blood, capillary refill time and blood pressure which are plotted on a chart in such a way that any deterioration becomes very apparent – very early. Wendy Sullivan from Starship, one of the developers of this chart, says that the coloured bands help users recognise more abnormal scores, especially when in juxtaposition to other observations. Graded points are allocated to different colours and when added up give a total score. This may then be an indication for the child's condition to be reviewed.

Wendy says that there has been a lot of interest in the PEWS chart, which has been in development for the last 2 years. "This chart gives confidence to junior doctors and inexperienced nurses especially. It can tell them that the child may need more frequent observations or it may give them the confidence to escalate calls to more senior staff," she says. "While this is a valuable tool to help identify a child in danger of deterioration, it can also help in the development of treatment plans, which specialist should review the child and if urgency is needed," she said.

The PEWS chart has age-appropriate values for the child's age, which are not as uniform as those for an adult. The tool has been used widely in the past in adult medicine, but is much more complex because of the variation in normals according to age. This will help create a common language between DHBs and if it is widely adopted, which is the intention, then we will have good and standard referral points between centres.

Wendy Sullivan

Your contributions We welcome thoughts, contributions and articles and notices of upcoming events. We anticipate publishing updates around every three months. Please email the editor, Lauren Young on lauren@laurenyoung.co.nz